

Introduction

The Arizona Long Term Care System (ALTCS) is a program under the Arizona Health Care Cost Containment System (AHCCCS), Arizona's Managed Care/Medicaid system. Arizona is the first state to bid its Medicaid long term care program competitively, just as it does with its acute, or medical care services. Competitive bidding allows ALTCS customers to benefit from choice – the same choice given to other AHCCCS members not receiving Long Term Care.

ALTCS is unique because the program includes an array of fully integrated long term care services such as home and community-based services (HCBS), case management, behavioral health and nursing facilities, along with a comprehensive medical care component. In 2000, Arizona awarded three contracts to health plans to provide long term care services in Maricopa County. Every new applicant and all existing consumers in the county now can select Lifemark Health Plans (now called Evercare Select), Maricopa Long Term Care Plan or Mercy Care Plan.

Arizona long term care project

To determine if Arizona's long term care system in general and ALTCS in particular are meeting the public's needs, AHCCCS established a Long Term Care Project in 2000 to:

- **Understand how customers view the overall long term care system in Arizona, and what services are important to them.**
- **Assess consumer satisfaction with case management, doctors and services under ALTCS, in both home and community-based settings and nursing facilities.**

This project was conducted in three phases. The first involved researching, designing and testing the survey that would be used. The second included focus groups with Baby Boomers and a telephone survey among Maricopa County customers of the Arizona Long Term Care System. The third phase – and the subject of this report – involved surveying customers after they had been given the choice of

switching health plans to see what, if anything, had changed with their satisfaction levels. Comparisons were made between members who remained with their current health plans and those who switched to another plan. The survey had a response rate of 70 percent.

Individuals who participated in this survey were either direct members of the care (consumers) or those who made decisions for the consumer about their care (proxies).

What you'll find in this report

This final report highlights survey findings that were statistically significant. It contains an overview, proxy information and comparisons with the actual customer, results of satisfaction levels among those who changed or did not change plans, and a summation containing policy considerations.

This information has been prepared for policymakers, the profit and nonprofit sectors, elected officials, all those who participated in this process and the people of Arizona. Research for this project was conducted by the Health Services Advisory Group (HSAG) under contract with AHCCCS and in consultation with a National Advisory Panel of health care professionals with long term care expertise. The project was funded by the Flinn Foundation of Phoenix.

Other sources of information

Because the research team wanted to provide all relevant data but not create a "data overload," a separate Data Book has been prepared to supplement the findings and interpretations of this project's satisfaction survey. We have included the most relevant of all data tables in the book "What Current Consumers Say" and placed all data tables in the "Survey Data Book." A reader wanting to review more detail or the entire set of data used to interpret the findings may obtain copies from the AHCCCS website, www.ahcccs.state.az.us.

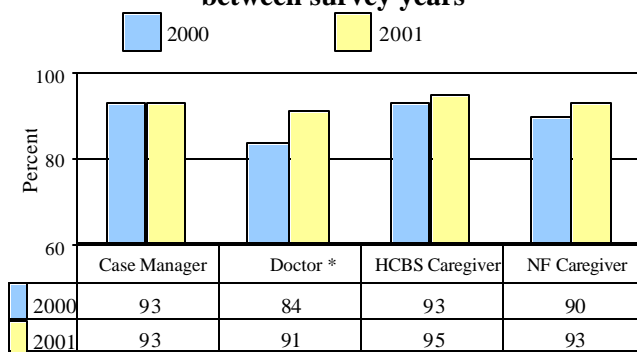
Overview: High satisfaction with ALTCS

Is AHCCCS taking care of long term care business?

That's what AHCCCS wanted to find out from ALTCS customers in 2000. Overall, survey results at the time indicated consumers were either very satisfied or satisfied with their health plan's case managers, doctors, HCBS caregivers and NF caregivers (see Figure 1). Then in 2001, after consumers had the opportunity to change health plans, they again were surveyed and the results were compared to the 2000 results

Notable between 2000 and 2001 was a change in the area related to services by doctors, which showed an increase of 7% in the overall satisfaction level. Additional measures within the doctor area also realized a statistical difference between 2000 and 2001. For example, doctors' listening skills, doctors providing the help the consumer needs, doctors' involvement of consumers in decision-making, and doctors' consideration of consumers' cultural needs all increased in satisfaction ratings between 2000 and 2001.

Figure 1
Overall satisfaction on survey areas
between survey years



* Doctor area showed a significant difference between survey year 2000 and survey year 2001.



Across all areas in both survey years, respondents maintain high levels of satisfaction. The doctor, home and community-based services (HCBS) and nursing facility (NF) areas even reported higher satisfaction levels in the second year. While the case manager area did not show such an increase, it is noteworthy that its rating held steady at one of the higher satisfaction levels.

Satisfaction with HCBS caregivers showed an increase of 2% in the overall satisfaction rating between 2000 and 2001, and satisfaction with NF caregivers showed an increase of 3% between the two years.

"The case manager knows his business and he tries to help in any way he can. He advises us about alternatives that we can choose to do for my mother."

- A survey respondent

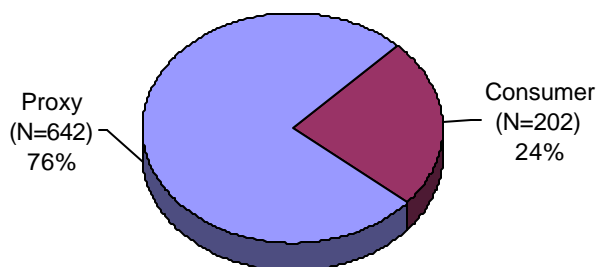
Proxies: They're ALTCS customers, also

While the customer of long term care services was the preferred respondent in our research, we found in an earlier survey (2000) that 73% of the consumers were unable to speak for themselves because of cognitive impairment. In such cases, researchers did not exclude these members and interviewed a proxy.

It is notable that although researchers expected a higher number of proxy responses among the NF group (89%), the HCBS group also had a surprisingly high number (64%). Hence, researchers determined that a better understanding of proxies would be beneficial.

In our latest survey (2001), we asked proxies additional questions to help us better understand the relationship between proxy and consumer. Of the 844 respondents to the survey in 2001, 76% were proxies (see Figure 2). This is similar to the first year of the study when 73% of respondents were proxies.

Figure 2
2001 - Is respondent the consumer or a proxy?



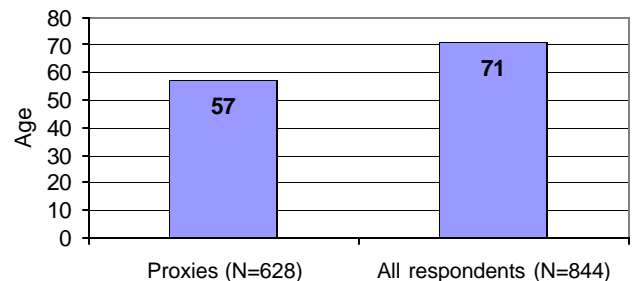
The type of relationship between proxy and consumer and the frequency of interactions or visits between the two was an indication of how well the proxy knew the consumer and whether he or she could answer questions about the consumer's care.

Questions regarding this area were added to the second survey. This provided AHCCCS with a picture of individuals assuming responsibility for the customer and a context in which to evaluate the survey results.

Proxy age and location

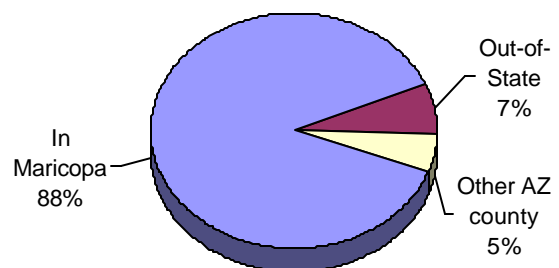
The mean age of proxies was 57, with a range of 26 and 96 years of age (see Figure 3).

Figure 3
Mean ages



Proxies lived predominantly in the Maricopa County area (88%, N=447). Only 7% (N=36) of proxies lived out-of-state, and 5% (N=26) of proxies lived in counties other than Maricopa County (see Figure 4).

Figure 4
Location of proxies
Total Respondents = 509



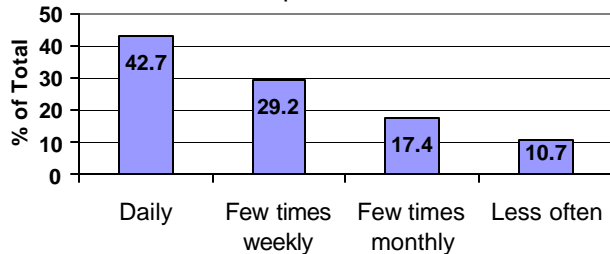
Proxy involvement

Researchers measured the degree of proxy involvement with a consumer to determine how involved the proxy was with the person's care. Nearly three out of four proxy respondents (72%) reported being involved with consumers either on a daily or weekly basis (see Figure 5). The high rate of involvement allowed the research team to analyze proxy data with a better comfort level

regarding how well proxies represented the opinions and perceptions of the consumer.

Figure 5
Degree of proxy involvement with consumer

Total respondents = 637

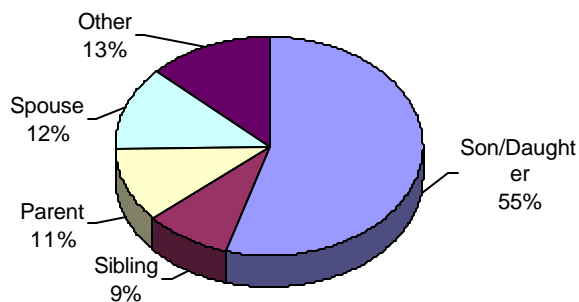


Type of relationship

In our latest survey, proxies were questioned about the kind of relationship they had with the consumer (see Figure 6). More than half of proxy respondents reported they were either the son or daughter of the consumer (55%), the spouse (12%), a parent (11%), a sibling (9%), or other type of relationship (13%).

Figure 6
Proxy relationship with consumer

Total respondents = 640



Support provided by proxies

Proxies also were asked to describe the kind of support they regularly provided to the consumer. The top two services were legal (76%) and help with financial matters (75%). In addition, 27% acted as paid caregivers for the consumer.

It should be noted that if a proxy functioned as a caregiver, they were excluded from answering questions where they would evaluate themselves.

Placement

As expected, a larger portion of consumers who resided in nursing facilities (89%) were cognitively impaired and had a proxy respondent for the survey. As for HCBS consumers, 64% were cognitively impaired and had a proxy as a respondent.

Comparing proxy & consumer data

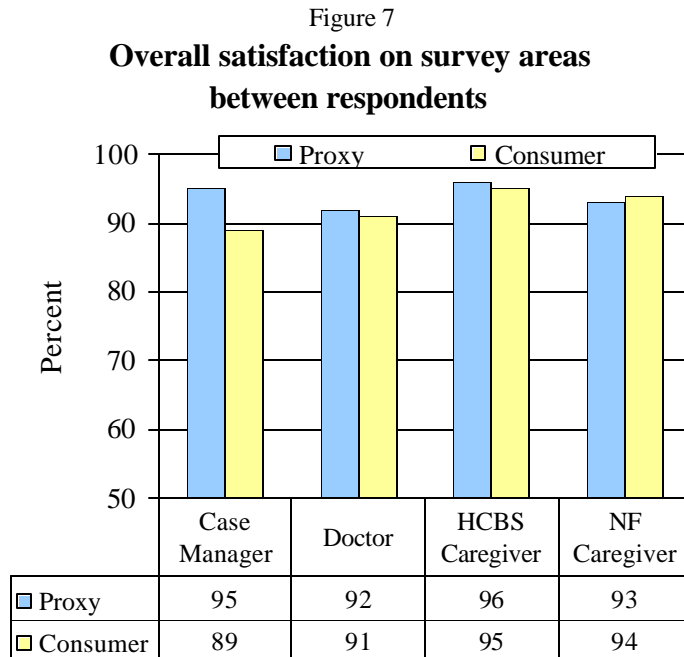
The following data compares the similarities and differences between proxy and consumer respondents on the four major survey areas: case manager, doctor, HCBS caregiver and NF caregiver. Each respondent was asked the same questions pertaining to persons providing services under each of the four areas.



The questions addressed: a) the person's listening skills; b) how the person involved the consumer in decision-making; c) how easily the person could be reached; d) whether the person provided the help the consumer needed; e) whether the person was respectful; and f) if the consumer's cultural needs were met.

Overall satisfaction

Figure 7 shows the satisfactions levels of both proxies and consumers in the four major areas of the survey: case managers, doctors, HCBS caregivers and NF caregivers.



Case manager area

Among the four major survey areas, measures characterizing the case manager category were the only ones in which there were statistical differences between consumer and proxy respondents. The differences, however, were not consistent. Some measures were rated high by proxies, while other measures were rated high by consumers.

Proxies rated case managers higher than consumers in overall satisfaction, listening skills, involvement of the consumer, the ease with which case managers could be reached, and the help case managers gave when needed. Consumer respondents, on the other hand, gave case managers a higher rating when it came to considering the consumer's cultural needs.

Doctor, HCBS caregiver and NF caregiver areas

There was only one doctor measure that indicated a statistical difference between consumer and proxy

respondents: More consumers reported knowing their doctor than proxy respondents.



Otherwise, there were no other statistical differences between consumer and proxy respondents in the doctor, HCBS caregiver and the NF caregiver areas.

"My case manager is absolutely great and caring and provides for my needs. I wouldn't be living on my own if it weren't for her."

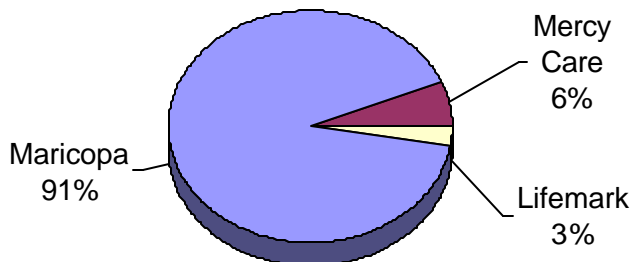
- A survey respondent

Satisfaction: What are the differences?

During the fall of 2000, ALTCS members in Maricopa County for the first time were able to choose from among three health plans to serve their needs: Maricopa Long Term Care Plan, Mercy Care Plan and Lifemark Health Plans. Before this, only the Maricopa plan was available.

Beginning in July, AHCCCS sent health plan enrollment choice information packets to 10,219 ALTCS consumers and/or their representatives who currently were enrolled under Maricopa's only plan. AHCCCS received responses from 10,176, or 99.6%. Of these, 9,225 (91%) chose to stay with Maricopa, 653 (6%) changed to Mercy Care, and 298 (3%) changed to Lifemark (see Figure 8). The 43 consumers who did not make a choice remained enrolled with Maricopa.

Figure 8
Selection of health plans

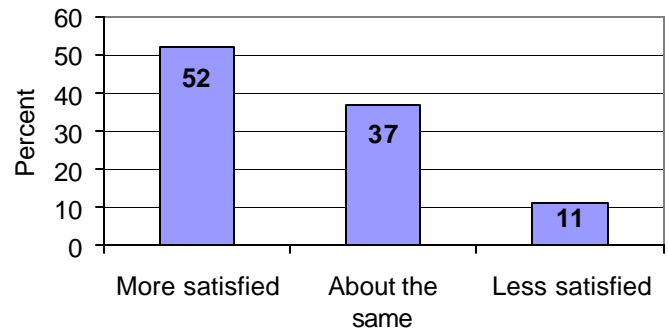


Of the 10,176 who responded to the mailing, 844 were chosen as a representative sample for the latest survey. Of those included in the survey, 174 elected to change health plans. No statistical differences were detected for gender or race/ethnicity between those who changed plans and those who did not change health plans. Of those who changed health plans, 52% reported they were more satisfied with their new plan; 37% reported that their satisfaction level between old and new plans remained the same; and 11% reported being less satisfied with their new plan (see Figure 9).

The reasons respondents cited most often for wanting to change health plans were location of a

hospital, the quality of a hospital, the quality of doctor's services and location of a doctor.

Figure 9
Comparison of new plan to old plan



Consumers who chose to remain with Maricopa Long Term Care Plan were not asked why they stayed with their plan. Such a high number of consumers choosing to remain with the Maricopa plan, however, indicates a high level of satisfaction with existing services.

The data that follows is presented according to the four major areas of the survey: 1) satisfaction with case managers, 2) satisfaction with doctors, 3) satisfaction with HCBS caregivers, or 4) satisfaction with NF caregivers. The questions asked are noted on page five of this report.

Satisfaction with the case manager

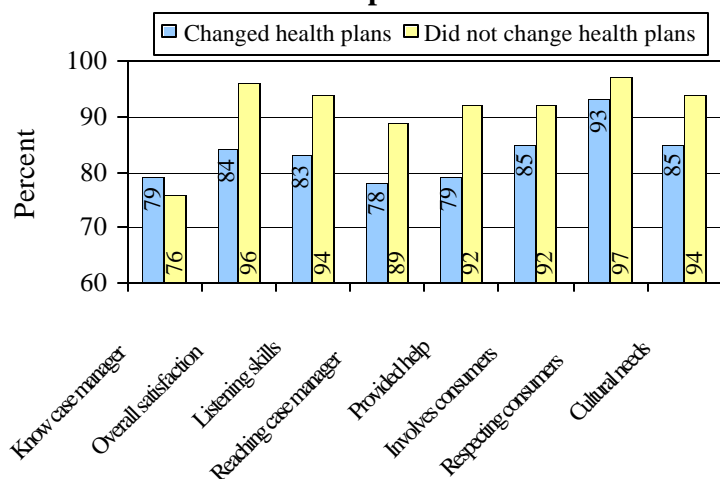
For the most part, those who did not change health plans showed a higher level of satisfaction under the case manager measures than those who did change health plans.

Knowing the case manager

Among those who changed health plans, consumer respondents were more likely to know their case managers (91%) than proxy respondents (75%). Additionally, HCBS respondents were more likely to know their case managers (94%) than NF respondents (63%) - see Figure 10.

Figure 10

Case manager area, comparison between those who changed and did not change health plans



Overall satisfaction

Respondents who did not change health plans were more satisfied with their case managers (96%) than those who did change plans (84%).

Respondents who did not change health plans were more satisfied that their case manager listens to them (94%) than those who did change plans (83%).

Reaching a case manager

Respondents who did not change health plans found it easier to reach their case managers (89%) than respondents who did change plans (78%).

Get the help needed

Ninety-two percent of those who did not change health plans were either very satisfied or satisfied they got the help needed from case managers. Of those who did change plans, 79% reported they were either very satisfied or satisfied that they get the help needed.

Cultural needs

Respondents who did not change health plans were more satisfied with how case managers considered cultural needs of consumers (94%) than were respondents who did change health plans (85%).

Satisfaction with doctor

Some ALTCS consumers have several doctors, including specialists, depending on their medical conditions, and whether they have Medicare. Every effort was made to ensure that consumers responded to the doctor-related satisfaction questions for their ALTCS primary care physician, and not other physicians, nurse practitioners, and/or physician assistants.

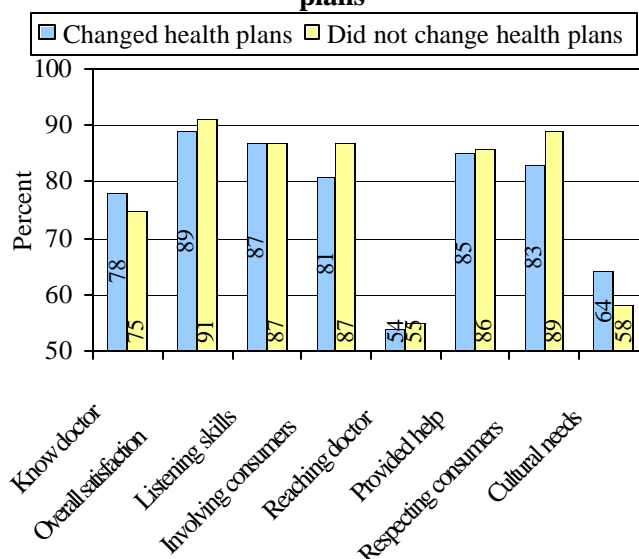
The study asked respondents a question that would assure that researchers were measuring the ALTCS plan's doctor and not a doctor outside of the plan's network. In evaluating the responses, however, consideration should be made that some overlap may have occurred.

Overall satisfaction

Figure 11 shows overall satisfaction results between those who changed and those who did not change health plans. Among respondents ages 65 and older (not addressed in Figure 11), those who did not change health plans were more satisfied with the overall performance of their doctors (92%) than those in the same age group who did change plans (86%).

Figure 11

Doctor area comparison between those who changed and did not change health plans



Knowing the doctor

HCBS respondents were more likely to know their doctors (84%) than NF respondents (70%).

Listening skills

Consumer respondents were more satisfied that their doctors listened to them (91%) than proxy respondents (85%).

Respondents ages 65 and older who did not change health plans were more satisfied with the listening skills of their doctors (87%) than those in the same age group who did change health plans (81%).



Respect

Respondents ages 65 and older who did not change health plans were more satisfied with respect shown by their doctors (90%) than those 65 and older who did change plans (80%).

Involving consumers

Respondents in the home were significantly more satisfied (88%) that doctors involved the consumer in decision-making than those respondents in nursing facilities (71%).

Get the help needed

Respondents in the home were significantly more satisfied (89%) than those respondents in nursing

facilities (77%) with doctors giving help to consumers when needed.

Easy to reach

Respondents living at home (64%) were more satisfied with their ability to reach their doctor than respondents in nursing facilities (59%).

Cultural needs

Respondents in the home were significantly more satisfied with their doctor's consideration of their cultural needs (69%) than those in nursing facilities (44%).

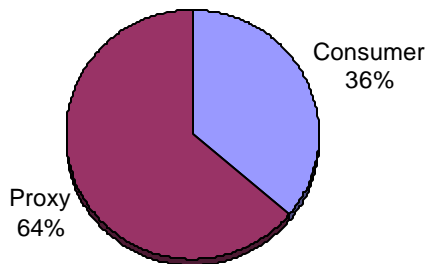
Satisfaction with HCBS caregiver

Fifty-one percent of the 844 survey respondents received HCBS services. ALTCS consumers who receive HCBS services may be living in their own homes, in the home of a relative or friend, or in an assisted living facility. Although ALTCS provides a wide range of HCBS services, each consumer's services are tailored to individual needs. Services may be provided by a variety of HCBS caregivers such as attendants, personal care aides, meal delivery aides, home health aides or nurses.

Since a consumer may be receiving HCBS services from several different providers regularly, the survey respondent was read a list of services available to HCBS consumers and was asked to identify the most important service available to the consumer. The respondent was then instructed to answer the HCBS caregiver satisfaction questions based on the consumer's relationship with the caregiver who provided their most important service.

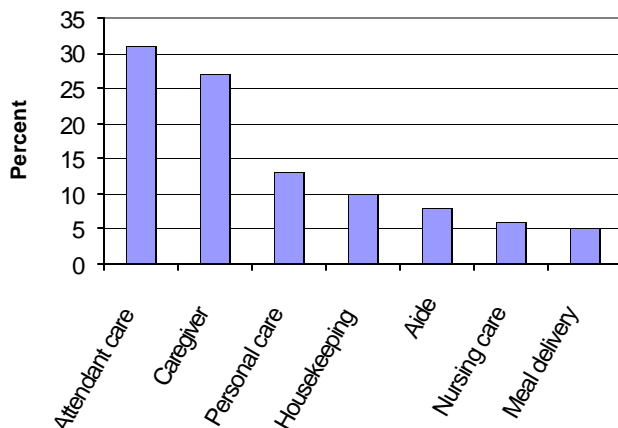
If proxy respondents ranked themselves as the caregiver, the surveyor did not ask questions about satisfaction with HCBS services; hence, proxies were not allowed to rate themselves. Of those respondents living in the HCBS setting, proxies represented 64% and consumers 36% (See Figure 12).

Figure 12
HCBS setting
Total respondents = 424



As depicted in Figure 13, respondents ranked attendant care as the most important service (31%), followed by proxy as caregiver (27%), personal care (13%), housekeeping (10%), aide (8%), nursing care (6%), and meal delivery (5%).

Figure 13
Ranking of HCBS services



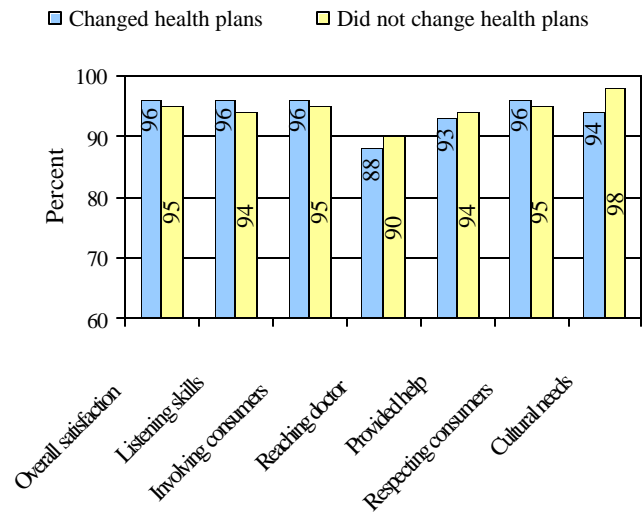
Attendant care was also considered the most important service among those who changed health plans (33%) and among those who did not change health plans (44%).

Again, no HCBS satisfaction questions were asked when the caregiver was the proxy and was ranked as the most important HCBS service.

Overall satisfaction

Satisfaction ratings for HCBS caregivers were very high (see Figure 14). Overall, 95% of the respondents reported that the consumer was very satisfied or satisfied with their HCBS caregiver.

Figure 14
HCBS area comparison between those who changed and did not change health plans



In addition:

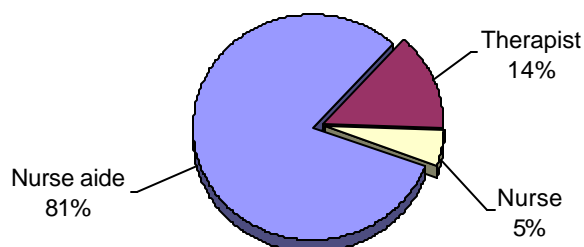
- 97% of the respondents reported being very satisfied or satisfied that the HCBS caregiver considered the cultural needs of the consumer.
- 95% of the respondents reported they were very satisfied or satisfied that the HCBS caregiver respected the consumer and involved the consumer in decision-making.
- 94% of respondents reported that the consumer was very satisfied or satisfied that the HCBS caregiver listened to the consumer, and that the HCBS caregiver was easy to reach.
- 90% of the respondents reported they were satisfied or very satisfied that the consumer received the help needed from the caregiver.

Only one significant difference was found between those who did not change health plans and those who did. Respondents reported that consumers ages 18 through 64 who did not change health plans (98%) were more satisfied with the HCBS caregiver's consideration of their cultural needs than consumers in the same age group who changed health plans (89%).

Ranking of NF services

ALTCS consumers living in a nursing facility may receive a variety of services to meet their long term care needs. Respondents were asked to select which of these services were most important to them. Services included nurses, aides, social workers and therapists. Of these, respondents were asked to indicate which service they felt was most important for the consumer. They were then asked to respond to satisfaction questions on that one service.

Figure 15
Ranking of services for NF consumers



Overall, respondents ranked nurse's aide (81%) as their most important service, followed by therapist (14%), and nurse (5%) – see Figure 15. Those who changed health plans and those who did not change health plans also ranked nurse's aide as their most important service (81% and 83%, respectively). There were no respondents who selected social work service as the most important.

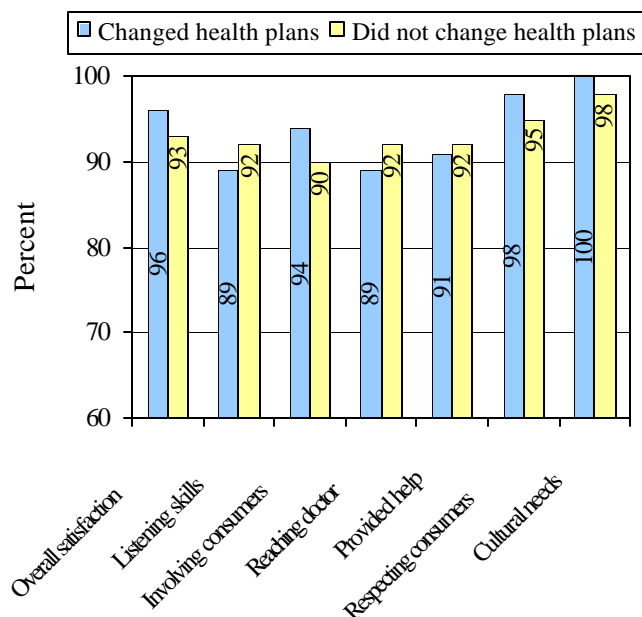
Proxy respondents who changed health plans found it easier to reach their NF caregiver (89%) than consumer respondents who tried to reach their NF caregiver (66%).

Satisfaction with NF services

There was, however, a significant difference found with the consumer stratification. Consumer respondents who did not change health plans were more satisfied with the overall performance of their NF caregiver (98%) than those consumer respondents who did change health plans (67%).

Figure 16 shows overall responses among all respondents who changed health plans and those who did not change. Those who changed health plans had higher overall satisfaction levels (96%). They also felt that the NF caregiver both involved the consumer more (94%), respected the consumer more (98%), and paid more attention to cultural needs (100%). Those who did not change health plans, however, were more satisfied with the caregiver's listening skills (92%), the ability to reach the caregiver (92%), and the caregiver providing help (92%).

Figure 16
NF area comparison between those who changed and did not change health plans



Provider help

One-hundred percent of respondents ages 18 through 64 were more likely to report they were very satisfied or satisfied that they got the help they needed from NF caregivers than did respondents ages 65 and over (89%).

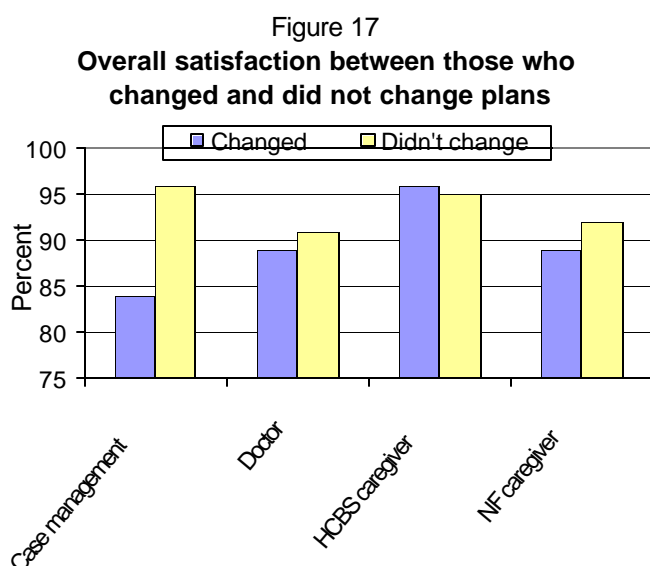
Policy considerations

The results of this final phase of research were used to develop policy considerations to guide state leaders and health care professionals as they continue to address long term care in the future.

After choice, how did health plans rate on satisfaction?

Very well. Depending on the health plan serving them, consumers were either very satisfied or satisfied with their plan 91% to 95% of the time. Specifically, consumers had high satisfaction levels with their case managers, doctors and caregivers in either home and community-based settings or nursing facilities. And it was the doctor area that showed the largest satisfaction increase from the years 2000 to 2001 – from 84% to 91%. Only “reachability” of a case manager, doctor or caregiver received a lower rating than in the first survey.

Whether respondents changed plans or not, their satisfaction levels within each of the four measured areas remained high, as show below:



Policy considerations :

- Monitor and compare the performance of health plans.
- Monitor which health plans are selected by new ALTCS members.
- Evaluate further the impact choice has on quality; on the rates paid to health plan by AHCCCS; and on providers, their networks and their rates.

Is the actual consumer the only ALTCS customer?

Not at all. Out of 844 respondents in the last phase of this project, 76% were proxy respondents while only 24% were actual consumers enrolled in the ALTCS program. This shows that in addition to the actual consumer, proxies are a valuable source of information because they are so involved with the care of the consumer.

There was little or no difference between the way proxies and consumers answered survey questions in all areas except the case manager area, where proxies showed a higher satisfaction level - 95% vs. 89%.

Policy considerations:

- Recognize that proxies are also key customers in the private and public long term care area.
- Obtain more data and learn how proxies impact care and services provided by long term care.
- Determine whether and how future surveys should be modified for proxy input.

Case managers: How are they viewed?

While it is less likely that consumers will change caregivers when they opt for service from another health plan, case managers are a different story. They do change because they work for a specific plan, unlike caregiver agencies that can contract with all available plans. It is noteworthy, therefore, that consumers and proxies in this research project reported an overall high rate of satisfaction (93%) with their case managers. This area had the most differences between those who changed plans (84% satisfaction) and those who did not change plans (96%).

Policy considerations:

- Health plans should evaluate case management to determine if there is increased improvement in this area among existing consumers over time.
- Continue to review and use best practices to accommodate new consumers when they become enrolled in a health plan.

Choice: What we know, what we don't

This research project answered some questions about choice but left many more unanswered. Across the country, comprehensive data about choice within the long term care arena is thin at best. It is still too new of a concept, particularly among Medicaid programs.

What we know from this project is that despite being offered a choice of three health plans, most consumers chose to remain with their existing plan – Maricopa Long Term Care Plan. We also know that of those consumers who chose to change health plans, the top four reasons were location of a hospital, quality of a hospital, quality of a doctor's services and location of a doctor.

What we don't know is why choice had such little effect on satisfaction levels, which remained high among those who changed and those who did not change health plans. We also don't know why so

many people chose to remain with Maricopa Long Term Care Plan. And we don't know if brand new customers of ALTCS make choices for different reasons from those already in the program.

It is not unusual that this project raised more questions than it answered because research is so new in this area. So is expertise to conduct this kind of research. But this is a starting point to determine where to go next both in research and in planning.



Policy considerations :

- Explore what differences motivate so many consumers to remain or not remain with their existing plan when choice is offered.
- Explore what motivates brand new ALTCS members to choose one plan over another.
- Promote more expertise in this kind of research.

Summary

What lessons did we learn to improve for future research?

As consumer involvement in long term care increases, states and health care professionals continue to look for the best ways to survey these consumers and their families. Time and money, of course, will restrict a survey that can address every area of interest among this population. Still, even a survey with limits will turn up valuable lessons for further research, as did this one. Some lessons include:

- Early in the planning, clearly determine the focus of the survey and how the data will be used both from strategic planning and operational efforts.
- If resources are scarce, limit the sample stratification and thus focus more time and analysis in key areas.
- To reduce the cost of the survey, explore ways to efficiently identify those customers who are cognitively impaired and need a proxy to respond in an efficient way.
- Before beginning research work, determine how proxy responses vs. consumer responses will add or detract from the survey, if at all.
- Standardize the way statewide surveys are worded and conducted so there is comparable feedback and the same baselines for further such surveys.

Long term care consumers in Maricopa County are extremely satisfied with their long term care services, whether they have changed health plans or not.

Proxies have emerged as an important party speaking on behalf of consumers, and will be included as a critical part of future research.

More research is needed to determine how much difference choice makes, why new consumers choose one plan over another and why consumers choose to remain or not remain with their existing plan.



ABOUT THE LTC SURVEY

To learn more about how to strategically plan for the future of our long term care systems in Arizona, the Flinn Foundation funded the first state Medicaid long term care consumer satisfaction survey.

ABOUT THE DATA

The quantitative data presented in this report was collected from participants of a consumer telephone survey. Individuals who participated were either direct members of the care (consumers) or making decisions for the consumer about their care (proxies).

ABOUT THE FINAL REPORT

This series, The Final Report is funded by a grant from The Flinn Foundation.

This report is the second in a series of four publications. Other documents available are:

1. What Consumers Say Book
2. Survey Data Book
3. Trifold – Final Report Summary

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